

Alabama Interagency Autism Coordinating Council (AIACC)

Monday, April 9, 2018

Alabama Industrial Development Training Center

The AIACC met on Monday, April 9, 2018, at the Alabama Industrial Development Training Center. The meeting was called to order by Chair, Senator Cam Ward. Also in attendance were Council members: Fred Biasini, Brooke Bowles, Robert Caldwell, Greg Carlson, Megan Everett, Doris Hill, Melanie Jones, Sarah Ryan, Todd Tomerlin, and Karen Willis. The following proxies were in attendance as well: Eliza Belle on behalf of Lynn Beshear, Sondra Landers on behalf of Nancy Buckner, Sonia Cleckler on behalf of Jane Elizabeth Burdeshaw, Nancy Thomas on behalf of Lucian Cronkite, Vera Hendrix on behalf of John Mascia, Justin Schwartz on behalf of Myriam Peralta, and Tina Sanders on behalf of Ed Richardson. Also in attendance was Anna McConnell, State Autism Coordinator.

The minutes from the January 29, 2018 meeting were approved and adopted.

Chairperson Comments: Senator Ward noted that April is Autism Awareness Month. The Regional Autism Network funding was not increased, but next year we expected an increased appropriation, as well as in funding for behavioral therapy. Eleven million dollars was allocated for behavioral therapy in the budget through various funds. A good portion of this funding is for people with ASD. While the economy has allowed for a decrease on the demands on the Medicaid system, Alabama runs one of the most bare bones Medicaid systems in the country, so service provision is still difficult.

Lead Agency Comments: Dr. Eliza Belle welcomed the group on behalf of the Department of Mental Health (DMH). She is Director of Behavioral and Psychological Services for DMH, Developmental Disabilities division. She has been at DMH for two months, coming from a Mental Health hospital system as a psychologist. Sen. Ward noted that the Commissioner has been fantastic to work with and appreciates the focus on Developmental Disabilities.

State Coordinator Comments: Anna McConnell noted that the Annual Report was distributed via e-news. Autism Awareness Month activities were included in the agenda – let us know if any activities were missed. Beth Johns and Martha Wingate are working on Strategic Planning and related activities for the AIACC. UAB's School of Public Health is performing a Rapid Needs Assessment to update data from the last Needs Assessment 10 years ago. The data collected should parallel in many ways to track progress and needs. Surveys will be distributed to families and providers and should be available soon. A link to those surveys will be sent out to the AIACC distribution list via e-news. Scripts for Key Informant

Interviews are being developed, and interviews will be conducted soon. This should provide a baseline for moving forward.

Membership/Bylaws Committee: Sarah Ryan reported that the Committee is still waiting on appointments and reappointments from the Governor's Office for the AIACC and the RAN Constituency Boards. Four committee members will be rolling off in September as they will be completing their second terms (Todd Tomerlin, Greg Carlson, Doris Hill, Sarah Ryan). These are three provider seats and one seat for a parent of a child age 18 years of age or younger that are opening up. Applications for these positions will be available on the AIACC website and hard copies are available. Applications are due June 1. Brooke Bowles asked if there are any parts of the state that are lacking representation for providers, and Sarah Ryan responded that there is a need for members from rural areas. Sen. Ward noted that we need to make sure members who are rolling off can still be involved in different ways. Anna responded that this should be achieved with the Strategic Planning to maintain and encourage involvement in the AIACC. Beth Johns noted that the Strategic Planning would make a presentation of findings in July's AIACC meeting.

Regional Autism Network Update:

Auburn: Doris Hill reported that the 2nd Annual Regional Autism Network (RAN) Conference was held in February, with Constituency Board members in attendance. They provided feedback and priorities for moving forward for the RAN. The RAN continues to serve those with diverse needs, not always just ASD. Doris has been serving families with multiple children with special needs. Outreach has been effective in Auburn's region. Professionals have been increasingly calling the RAN for Technical Assistance and Training to better serve their clients and patients. The Auburn RAN has been working with local advocacy groups to provide assistance to families. A presentation was given by the Auburn RAN at the Alabama disAbility Conference in Montgomery. The listserve is up and running and continuing to be developed, along with a website. May 3 is the next Auburn RAN Constituency Board meeting. The RAN Strategic Planning meeting will be in Auburn on June 11. The RAN directors met earlier in the morning with Gail Sheldon from the Public Library Service, as well as Todd Shipman, the Auburn RAN Constituency Board Chair and the Educational Librarian at Auburn University to look at ways to collaborate.

University of Alabama: Anna McConnell noted that Sarah Ryan has moved to UAB and Sparks Clinics, and Angie Barber is the new interim RAN Director. They are currently working on hiring a RAN Director and changing location among departments. They are in the first year and are working to get feet on the ground, as all RAN sites have done the first year.

UAB: Lizzie Griffith echoed Doris Hill about the good discussions that occurred with the Constituency Boards during the RAN Conference in February. The RAN phone line will be moved to a RAN team location. The RAN contact information is being given at time of diagnosis to families and helping with connecting to resources, and those families have been able to attend RAN Workshops. Nurse Practitioners have been calling frequently and Lizzie has been able to connect them with Project ECHO when appropriate. A Professional Training has been requested from the GI department at Children's of AL. The Community Education Workshops have been a popular source of information for caregivers and providers. Three have been held this year, with 100 families reached. The Steering Committee will be meeting in May to discuss the 2019 year's topics. Particular attention has been given to Spanish speaking families in partnership with Help Me Grow and Autism Society of Alabama. They expressed a sense of isolation, and this has been a nice way to include that community. Videoing of the workshops is coming along, and April should have videos available of parent perspective of navigating school issues. The hope is to post it on the Sparks' YouTube page and in partner organizations. Data collection in regard to workshops we hope will show effectiveness. Anne Brisendine and Christian Clesi have been working on the IRB and data collection piece of this project. The research piece will collect data on demographics (ages of children/families reached), effectiveness of the workshops (increase of knowledge), and implementation effectiveness post training.

USA: Amy Mitchell said that assistance has been provided to 44 individuals – with the most questions coming about where to get a diagnosis for kids ages 5-15. Questions about services outside the school system and services for adults are the other primary questions asked of the USA RAN. Technical assistance requests from grad students working on dissertations and university personnel writing grant proposals wanted to know needs in the region. The USA RAN has reached 105 professionals through training. There are lots of requests for public education – those will be scheduled soon. Dr. Swingle and Dr. Anderson will be doing some of that public education in the coming months. The Autism Matters Conference, cosponsored by Autism Society of Alabama and USA RAN is sold out. The USA RAN is co-sponsoring an event with the College of Allied Health at USA, the TIPP Program (Team-Based Interpersonal Personnel Preparation). This will be a certificate program that allows participants to get more training in autism beyond their program requirements. There will be a conference open to the community too. Amy asked Sen. Ward for clarification on contacting legislators. He said to make phone calls, invite legislators to see what they are doing in the community and in the university. For example, the Mobile delegation would like to hear what you are doing. When budget discussions arise, they may be more likely to support because they know what the RAN is.

Public Awareness: Melanie Jones noted it is Autism Awareness and Acceptance Month. There are 15-18 walks throughout the state sponsored by Autism Society of Alabama. ASA has reached out to all the

Special Education Coordinators in the state. Autism Friendly Alabama is still moving forward and will be partnering with Triumph. Melanie said that there are packets that are distributed to businesses who become Autism Friendly. Ear plugs, a sensory toy, and sunglasses are included in those packets, as well as some training are provided to the business. Regions Bank will also be working on banking informational materials more usable for those with autism and other developmental disabilities. Dr. O'Kelley and Dr. Schwartz will be working with Regions on this project. Dr. Biasini noted that the Self-Advocacy Conference will be held in uptown Birmingham in June. He asked if ASA could approach restaurants about becoming autism friendly.

Finance: Greg Carlson noted that at the April 6 Behavior Analyst Licensure Board meeting, 19 additional licenses were issued. Marc Williams said that should make the total number to just under 200 licensed (included BCBAs and BCaBAs). July 1 is the deadline to become licensed. You won't be able to provide ABA in AL without a license after that date. Marc Williams praised Paige McKerchar's efforts in starting this effort, and keeping things moving along successfully. Coverage for ASD has been offered for State Employees (SEHIB) and Public Education Employees (PEEHIP). PEEHIP allowed for retroactive coverage of ABA to January 2018. Nancy Thomas from New Directions Behavioral Health said they have 70 providers credentialed with New Directions Behavioral Health (NDBH) (for Blue Cross Blue Shield of AL and EPS contracts). She offered her assistance for getting providers in the network. NDBH is planning provider meetings on May 2 and 3 (in Birmingham and Montgomery). You don't have to be credentialed to attend the informational meetings. Bama asked about parents who call PEEHIP and are told PEEHIP doesn't cover ABA. Nancy recommended families call provider relations or herself. While NCBH does the credentialing, BCBS also needs the information in their system as well. Greg asked if PEEHIP is backdating to January 1 – Nancy said backdating would go back to when the provider is credentialed and approved. Nancy said they are trying to get more providers in the network since it's such an underserved population. Amy Mitchell asked if there would be any provider meetings in South Alabama. Greg noted that public coverage has been in the works over the past couple years. On Friday, the Governor announced the settlement of EPSDT. Nancy Anderson and Geron Gadd led a discussion on the services coming online due to the agreement. Anna distributed the service definitions to the group. Geron thanked the Governor and legislators involved in the appropriations for these services, as well as the agencies who have been working to expand services for children with ASD, including those with SED, and ASD with co-occurring IDD. One of the primary questions received has been "is ABA included?". The answer is "yes", ABA is included, but it is not the only service provided for in the In Home Behavioral Support service category. We are working with other agencies and stakeholders to create something that did not exist before. There is a timeline – we anticipate that at the July 9 AIACC meeting, further details will be available. ADAP Associate Director Nancy Anderson

has led this effort from the beginning. Nancy began a listening session with the group, as the definitions were provided for review. Below are questions and concerns expressed by AIACC members and attendees during the listening session, which will be conveyed to the ASD Working Group. Responses to questions are recorded as well:

- **How will providers be enrolled into the Medicaid program to provide ABA services?** We are working on that now and building the ship to prepare for October 1.
- **In realizing how long it takes to get the Medicaid Plan amended, how is that going to happen between now and Oct 1?** *Edited to include correction: The ASD State Plan Amendment has not been submitted to CMS yet – that is expected later this summer.* ABA will be included in In Home Behavioral Support. In 2014 CMS issued guidance about this. The codes are being worked out, but those interventions will be available. There should be more information by July. Outreach will be done with families and providers in how to access services and provision of services.
- **It says “In-Home Services”. Do they really have to be provided “In Home”?** No. The better term is “in community”. All services do not have to be provided in the home, but they may be provided in the home. It is a natural environment intention that could include in home, community, and school.
- **The monies that are identified in the budget were allocated to Dept of Mental Health. When talking about SED population, they are already served there. For the ABA services, would that be provided by DMH as lead agency?** Yes, but the structure is still being built.
- **Would it be under the Rehab Option?** The mechanics are being built. It wouldn't necessarily fall under the Rehab Option chapter.
- **Who would be providers of In Home Therapy? Those certified in Behavior Analysis?** That is being decided right now. Recommendation from audience: if behavior analysis was added to that definition, it should be board certified (or assistant or RBT) in collaboration with appropriate professionals.
- **Peer Support has not been covered by Medicaid through a waiver program. Has that been worked out?** What you see is what will be provided due to settlement agreement.
- **Peer support – do we already have a system in place for certifying peer specialists? Is there a directory?** The Peer Support system in this program is being worked on. The committee is borrowing from other states and in our state in the MI system. Gleaning best practice from variety of realms for this population. Audience: we want trained and well qualified people, but don't want to waste time to go through curriculum to become certified. It should be able to apply current expertise and education towards that and not go through new system of training.

Don't want to have to check all the boxes when they have a set of skills. Certification was not popular with those that spoke.

- **HP doesn't pay for services for any therapeutic interventions for those with ID diagnosis.** It is written IDD to make sure co-occurring doesn't disqualify services. Audience: it is an HP issue. Medicaid will not reimburse if diagnosis is ID. Even refuses when showing them Chapter 34, so diagnosis code is not always reflective of child. Geron: Medicaid is active in this process so hopefully will address those concerns, as it will come with lots of education of providers. Audience: Medicaid isn't the issue, it's the billing group (HP). The problem is widespread. Nancy: we can learn from the private coverage rollout, especially to that level.
- **For Intensive Care Coordination, what is the expected caseload? Many state agencies have large caseloads and it is difficult to serve clients. How long will that individual stay on caseload? How do you determine which caseload they go on so as not to overload the worker?**
- **SED/MI was speaking about SED and certification. Are providers certified as an (for example) SED/DD providers—will there be a provider certification for ASD as a whole?** That is part of the structure being worked out now.
- **For In Home Behavioral Support, the wording in the definition sounds like you are describing a BCBA, but says it's not limited to that group. Who else would be qualified to do that? Positive Behavior Support Therapy – high rate/high intensity behavior may need non-positive techniques that are evidence based (i.e. timeout). This is a small population, but the literature suggests they don't benefit from positive behavior support only. What are your thoughts there?** This behavior support definition includes but not limited to ABA. Tried to be overly inclusive rather than strictly inclusive. Today, there is lots of evidence about ABA, what happens 5 years down the road? Audience: when left unlimited, there is a concerted push toward less intensive and less expensive therapy. It becomes harder to get folks what actually helps them. For example, in another state, the Dept of DD would pay for behavior analytic services, but would also pay for Play Project (1 hr/week and less expensive with little training). At the County Board level, they would say "you don't want your 3 year old through so many hours of intensive intervention, do the play therapy at 1 hour/week, and less expensive". Over the years, those counties did not have BCBA's and folks weren't getting helped, IQs were not increasing, and continued to need services for the rest of their lives, whereas 30-40% could have moved on to be taxpayers and contributors. It is very short sighted. Nancy – make sure that the criteria that is developed for this category of service doesn't get watered down to the lowest common denominator. Audience – evidence-based threshold. Evidence for what? For example – use a treatment that has evidence based that it can bump IQ by 2 standard deviations in a sizeable percentage of the

population. Something that has social validity. Something else might have evidence that parents like it, but is that where we need to spend Medicaid dollars?

- **Who is going to be looking at who is providing what services? For all of the services, who will be overseeing the provider (definitions and as services being provided)?** Nancy – working group will develop this as rigorously and detailed as possible. Geron – this will be monitored over a period of time due to settlement agreement. There should be a natural distribution of services being available because these are new services. The higher level, more intense services would be needed more at the outset, but over time the natural distribution should kick in. If only lowest level of services being provided, then it would give those involved in implementation of this a reason to say it doesn't make sense and give a harder look at what is being implemented.
- **Having worked in Massachusetts, before there was an RBT designation, there was a number of different titles and different pay scales. Now there is specific course work that has helped ensure system is knowing who is providing the service and what it takes to get there (helped providers and insurance companies). Be sure to use appropriate titles, credentials, and definitions (BCBA, BCaBA, RBT, etc.)** The RBT came up at last meeting and discussed heavily.
- **There are case managers for SED and ID, and care coordinators in health home model. These terms are confusing for families and agencies. The concept of care coordination depends on who you ask. To ensure highest quality of care coordination, nomenclature matters across systems. The Spanish population will be a group to pay special attention to – it is difficult even with translation services. Keep non-English speakers in mind.** Lots of discussions about cultural and linguistic competencies.
- **Therapeutic Mentoring seems to be like a coach – what age group is this envisioned for?** 0-21 being available throughout age spectrum. Would it be more beneficial for one group than another? Audience – transition focus more likely, but should be made appropriate throughout 0-21.
- **Nancy asked the group about Peer Support – peers are usually thought of as people with lived experiences, like in MI. But the ASD Working Group said it might be helpful to have someone without autism modeling as a peer. Is there a role for both?** Audience – yes.
- **Would substance abuse qualify for EPSDT?** No, it's based on financial eligibility Medicaid rules.
- **Family Support – what is best thing we can do for families to understand nature of illness and how to help their child?** Audience: Are there any 2 services that you would recommend together? It seems therapeutic mentoring and FS would go well together. FS seems to be key to any of the other services. Nancy – if child has ASD and are Medicaid eligible, their entrance to any service is their need for it. Audience – wouldn't that be part of the treatment plan? If provide that part of service, the parents would have to be included. Nancy said the issue at hand is being able to

bill for it. Medicaid said FS would need to be renamed to Psychoeducational Supports. Audience: Sibshops, social skills and training, for example. Respite care is greatest need for family and shown to reduce healthcare costs – we need to use other terminology to try to get it covered. Geron said the group is mindful of Medicaid billing to be able to bill for 2 or more services at the same time-- to make sure billing codes don't preclude another service. Don't want offered in theory but practically inaccessible. Audience – Sibshops and PEERS are a service and not a "help understand". When they read definition, they think of Parent-to-Parent mentoring or something similar. ASD WG member – parent to parent is included in work. One of most common requests of need is support for worship. That fits in community services. The behavioral therapist should be able to be provided when those services are offered. Audience - It is both support for families and ways for family to support individual. These services must be structured in a billable way. IEP Advocate might fit here. Nancy – if a school utilized a Medicaid provider, the school could use these services to support a child in that school setting. Respite is one of most requested needs of providers in the state. Transportation is a major issue (Medicaid has non-emergency transportation). Education might not be all – might be to carry over services

The meeting was adjourned at 12:00 p.m.

Next meeting: Monday, July 9, 2018

Recording Secretary

A. McConnell